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Caring about student carers

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Caring about student carers

Carer research group

Defining carers

A carer is anyone who **cares, unpaid, for a friend or family member** who due to illness, disability, a mental health problem or an addiction cannot cope without their support
(*Carers Trust, 2017*)

The ever-increasing demand for carers

2001
2%

2011
12%

2019
15%

8.8 million people

in the UK are currently caring



3 in 5/60% of us

will be a carer at some
point in our lives



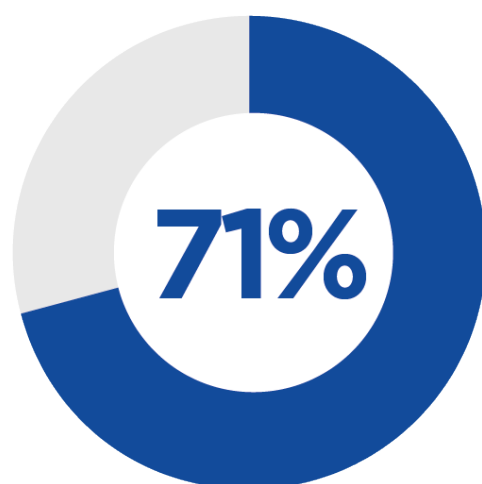
More and more people are
likely to care

**more than once in
their lifetime**

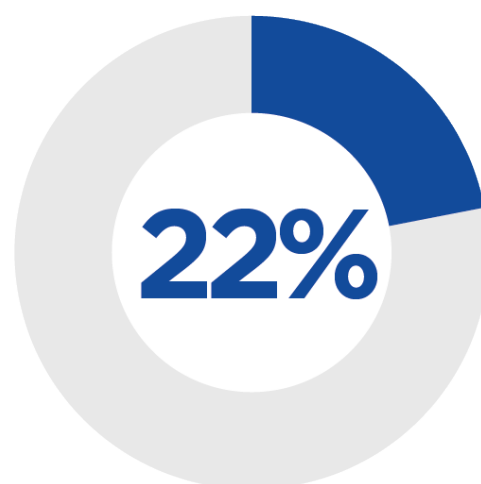
and be a sandwich carer

Carers and caring

Carers are often disadvantaged in health and wellbeing



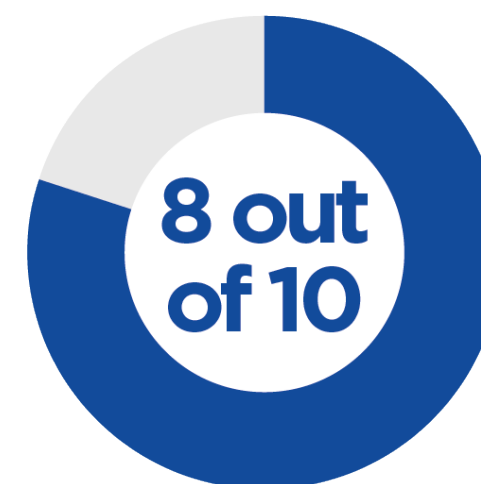
71% of carers have **poor physical or mental health**



22% **live in poverty**

Young adult carers (aged 14-25) have **lower GCSE attainment** and are **twice as likely as their peers to be NEET** (not in employment, education or training) for six months or more

Nearly half a million people (468,000) have given up work over the past two years as a result of caring



8 out of 10 have felt **lonely or socially isolated** as a result of their caring role

The demands on carers are likely to increase

Background to the study

- currently 5,422 OU students have declared caring status
- numbers of students with caring responsibilities will rise
- increased OU concern about supporting carers - Access and Participation Plan target to decrease non-declaration rate from 95.4% to 0% by 24/25
- little research about student carers generally and within the OU
- Research and Scholarship study carried out by 5 members of the Carers research group (part of the Care and Caring Network@OU - <http://intranet6.open.ac.uk/staff/ou-caring-network>)
- the first in a 2-phase project - part of a cluster of HWSC scholarship projects looking at how personal challenges affect study, persistence and retention
- focusses on gaining a better understanding of students who are carers and how to support them. Its aims were to:
 - explore how students who are carers experience and manage (OU) study
 - provide a foundation for further University-wide research in this area

Methodology

- a qualitative study that ran from January - September 2019
- 20 telephone interviews (supported with a topic guide) were conducted by a PhD student with HWSC students with caring responsibilities
- sample: 16 females and 4 males; 12 were caring for one person; 5 had caring responsibilities for a child with complex needs, 4 for a parent, 2 for a partner and 1 for a brother; 8 had (or had in the past) multiple caring responsibilities; 11 were combining care, study and full or part time work; duration of caring responsibilities ranged from 2 to 23 years; most were part of a family carer network (e.g. siblings) as opposed to being solo carers
- caring circumstances were both dynamic and evolving with a few reporting transitioning in and out of caring while others were experiencing ever-increasing caring demands and shifts in the type of care required
- the interviews were transcribed

Analysis

- the data was analysed using an approach based on Thematic analysis
- the first stage involved each of the project team members familiarising themselves with, and thematically coding, 4 scripts
- the project team then met and using their notes taken during the familiarisation stage, developed a thematic framework based on the key issues, concepts and themes
- in order to filter and classify all the data, the thematic framework was transferred onto an SharePoint excel sheet on which team members inserted summary points and quotes from their 4 transcripts that corresponded to the codes
- frequency analysis of the codes was undertaken to identify the most commonly occurring (plus exceptions)



1. Caring and studying

- positive aspects of caring: acquisition of specific skills and qualities, some of which were useful in their workplace roles; rewarding and emotionally satisfying to make the person for whom they care 'happy and contented'
- pressures of caring: many faced intense and challenging levels of caring; unpredictable nature of care; not having enough time to study or uninterrupted study time (exacerbated by financial pressures)
- effects on studying: behind on reading; unable to concentrate or enjoy their modules; unable to attend live tutorials and be part of a collective; feeling stressed because they could not submit their assignments on time; feeling 'drained', 'tired', "beyond tired" 'knackered' and 'exhausted'; close to giving up on studying or had failed a module previously

2. Benefits of studying

- studying referred to as 'me time' and a valued distraction from caring
- although some experienced guilt, it was seen as being enjoyable and as a substitute for social or leisure activities
- increased their confidence and resilience
- gained a better understanding of care and caring (including relevant legislation) and this understanding meant they could now provide a better quality of care
- beneficial to, and created a vision for, potential career and employment

3 Studying with the OU

- the OU's flexibility and affordability were two key factors that influenced students' decision to choose the OU
- students implicitly acknowledged the OU's open access policy and saw the OU as pivotal in meeting their personal expectations for growth and development
- where students were more negative it was about the loneliness of OU study; learning materials that failed to feed into their preferred learning preferences; work placements for social work students; and the timing of assignments (e.g. in school holidays)

4. Coping with OU Study

- managing the pressures of caring and studying alongside other commitments is tough, and sometimes overwhelming
 - pragmaticism: many accepted caring comes first, that 'you just get on with it', and all was not lost if they did not achieve their goals.
 - coping strategies used:
 - learning to 'go with the flow' and replanning when study time dissipates
 - working around their caring responsibilities
 - careful time management and
 - being 'a bit ahead of the game'
 - strategically planning and taking time off work to manage their study
 - setting clear boundaries wherever possible and managing other people's (mostly those who were being cared for) expectations
- NB.** irrespective of the success of these strategies, participants invariably experienced guilt when taking time away from caring
- importance of immediate and wider family, friends and community to coping with study

5. OU Support

- many said the OU provides 'good support'
- important role provided by their tutors: the best tutors had been proactive in their contact with students, clarifying their role and accessibility and establishing clear expectations for students.
- where students had spoken to tutors about their caring responsibilities these tutors had responded appropriately and supported them when they experienced challenges e.g. in requests for extensions on their assignment submission dates
- not all students had disclosed their caring responsibilities, mainly because they had not seen themselves as carers, saw it as 'my issue' or did not think available support would help them
- concern about being eligible for support if a formal diagnosis had still to be reached on the person receiving care and how carers evidenced their caring role
- where mental health was the focus of the caring role, students felt that this was often misunderstood by the OU with little direct support available to carers supporting others with these needs

6. Suggestions for improving OU students with caring responsibilities

- return to some elements of face-to-face tuition to increase the visibility of their peer community but there were also comments that access to Day schools etc. was often impossible due to geographical distance and ongoing caring responsibilities
- peer support facilitated through learning design was a way forward in combating the loneliness of OU study
- financial support to help them cope with studying whilst caring
- assignment management: no submission dates in school holidays and waive University rule about no extensions on End of Module assignment/examination for student carers

Discussion

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In terms of frames Billett's (2008) concept of co-participation these finding can be seen in terms of:

- **Affordances for study**

- caring had shaped the contours of the participants' life and also prepared them for the for the demands of studying
- distance learning offers student-carers certain affordances which are more compatible with the demands of caring than conventional education in terms of affordability and flexibility

- **'Me-time': the construction and negotiation of student-carer identities**

- while studying represented 'me time' to some, it could sit uneasily with their sense of personal integrity. Some student-carers felt guilty about prioritising their own needs over their caring responsibilities.
- for others, their interpretation of studying while caring can be viewed of 'biographical recasting' – reinterpreting their present actions in the light of a particular imagined future

Future directions

- group-based student support is not always appropriate as student carers can find personal support from their primary personal support networks
- the 'standard' OU model of group support may need to be supplemented with individual support
- insight into carers' needs should underpin support (e.g. in relation to documentary evidence to support requests for extension)
- more flexible modules e.g.
 - multiple options for tutorial sessions
 - removing examinations in modules
 - building fallow periods into modules
 - providing 'fast track' reading routes
 - proactive student support
- follow-up interviews with the same students are planned in the second of this two-part study